

## Specification for Carers Assessments data collection

### Version history

Version	Date	Status	Author	Issued to	Comments
0.1	10/5/2016	Draft	Martin Devine		Initial draft
0.2	26/5/2016	Draft	Martin Devine		
0.3		Draft	Martin Devine		
0.4	7/7/2016	Draft	Julie Rintoul		Sent to working group

## Variables included in this data collection

<b>Carer</b>
LocalAuthority
<b>IDCarer</b>
CHI
Surname
Forename
Postcode
PostcodeComp
DateOfBirth
Gender
EthnicGroup
CareHours
CareType
CareLevel

<b>Cared-for person</b>
<b>IDCarer</b>
<b>UniqueID</b>
CHICFP
SurnameCFP
ForenameCFP
PostcodeCFP
DateOfBirthCFP
GenderCFP
EthnicGroupCFP
ClientGroupCFP

<b>Additional for YCS</b>
<b>IDCarer</b>
RespAuthority
AppCare

<b>Assessment</b>
<b>IDCarer</b>
CAReq
CADate
CAType
CAComplete
CADeclined
DeclineDate
CADateComp
CACarer
CAWilling
CAEligible
CASupportNeeds
CASuppNeedsOther
CASupportProv
CASuppProvOther
CAReviewOutcome
CAReviewCrit

### Data collected through Social Care Survey:

The following data is already collected through the Social Care Survey. If a carer receives support through Self-Directed Support then they should be included in the Social Care Survey. For more information about the Social Care Survey see:

<http://www.gov.scot/Topics/Statistics/Browse/Health/SocialCareSurvey>

Person data
LAcodes
UniqueID
CHI
Surname
Forename
Postcode
Date of Birth
Gender
Ethnic Group
Person lives alone
Person has Carer
Type of Housing
Care Plan Date
IoRN Date
IoRN score
During Census week
Housing Support
Hot Meal service
Frozen Meal service
Home Care service
During financial year
Social worker support
Community Alarm
Telecare
Self-Directed Support

Client Group data
UniqueID
ClientGroup
<ul style="list-style-type: none"> <li>• Dementia</li> <li>• Mental Health</li> <li>• Learning Dis</li> <li>• Physical Dis</li> <li>• Addiction</li> <li>• Palliative Care</li> <li>• Carer</li> <li>• Frail elderly</li> <li>• Other</li> </ul>

Homecare data
UniqueID
LaHoursS
LaHoursA
OthLaHoursS
OthLaHoursA
PriHoursS
PriHoursA
VolHoursS
VolHoursA
MultiStaff
PersonalCareS
PersonalCareA

SDS data
UniqueID
SDS1 (yes/no)
SDS2 (yes/no)
SDS3 (yes/no)
SDS start date
SDS end date
SDS total package value
SDS1 package value
SDS2 package value
SDS3 package value
Contributors to SDS package
<ul style="list-style-type: none"> <li>• Social Work</li> <li>• Housing</li> <li>• Independent Living</li> <li>• Health</li> <li>• Client</li> <li>• Other</li> <li>• Not known</li> </ul>

Assessed Needs
<ul style="list-style-type: none"> <li>• Personal care</li> <li>• Health care</li> <li>• Domestic</li> <li>• Housing Support</li> <li>• Social / Educational</li> <li>• Equipment and Adaptations</li> <li>• Short Breaks / Respite</li> <li>• Meals</li> <li>• Other</li> </ul>
Support
<ul style="list-style-type: none"> <li>• Employs personal assistant</li> <li>• Purchased from LA</li> <li>• Purchased from private sector</li> <li>• Purchased from voluntary sector</li> <li>• Purchased from other source</li> </ul>

## Introduction

These notes have been prepared by the Scottish Government to assist local authorities with the collection and submission of data on carers' assessments.

Please note that this is an initial draft of the data specification, and is being issued for comment. In particular, we would welcome feedback on:

- any relevant data on carers' assessments collected by local authorities that is not included in this specification
- data items that are not collected by local authorities
- data items that would be difficult or time consuming for local authorities to collect

## Scope of collection

Data should be returned for all individuals who have requested or been offered an Adult Carer Support Plan or Young Carer Statement during the period.

(Need to specify this carefully - want to be sure that every carer possible is included, and it would be possible to either exclude some or receive incomplete data if the wrong condition is used.)

## Definitions

Adult Carer Support Plan (ACSP): A plan prepared by a responsible local authority setting out:

- (a) an adult carer's identified personal outcomes
  - (b) an adult carer's identified needs (if any)
  - (c) the support (if any) to be provided by the responsible local authority to an adult carer to meet those needs
- [\(section 6\(1\) of Carers \(Scotland\) Act 2016\)](#)

Young Carer Statement (YCS): A statement prepared by a responsible authority setting out:

- (a) a young carer's identified personal outcomes
  - (b) a young carer's identified needs (if any)
  - (c) the support (if any) to be provided by the responsible local authority to a young carer to meet those needs
- [\(section 12\(1\) of the Carers \(Scotland\) Act 2016\)](#)

Carer: An individual who provides or intends to provide care for another individual (the “cared-for person”), except where:

- the care is or would be provided under or by virtue of a contract, or as voluntary work.
- in the case of a cared-for person under 18 years old, to the extent that the care is or would be provided by virtue of the person’s age

([Section 1 of the Carers \(Scotland\) Act 2016](#))

Young carer: A carer who is either under 18 years old, or has reached age 18 while still at school, and is still at school.

([Section 2 of the Carers \(Scotland\) Act 2016](#))

Adult carer: A carer who is at least 18 years old, and not a young carer.

([Section 3 of the Carers \(Scotland\) Act 2016](#))

Responsible local authority: The local authority for the area in which the cared-for person resides. ([Section 41 of the Carers \(Scotland\) Act 2016](#))

## Questions and data definitions

### Carer data - one record per carer

Variable Name	Description	Format/Values	Additional information
LocalAuthority	The local authority that has offered or provided an assessment for the carer. This will be the 'responsible local authority', as defined in the Carers Act, i.e. the local authority for the area in which the cared-for person resides	100 Aberdeen City 110 Aberdeenshire 120 Angus 130 Argyll & Bute 150 Clackmannanshire 170 Dumfries & Galloway 180 Dundee City 190 East Ayrshire 200 East Dunbartonshire 210 East Lothian 220 East Renfrewshire 230 Edinburgh, City of 240 Falkirk 250 Fife 260 Glasgow City 270 Highland 280 Inverclyde 290 Midlothian 300 Moray 235 Na h-Eileanan Siar 310 North Ayrshire 320 North Lanarkshire 330 Orkney Islands 340 Perth & Kinross	This must be provided for all carers.

Variable Name	Description	Format/Values	Additional information
		350 Renfrewshire 360 Shetland Islands 370 South Ayrshire 380 South Lanarkshire 390 Stirling 395 Scottish Borders 400 West Lothian	
IDCarer	Unique identifier for the carer.	Numeric/Character	<p>This must be provided for all carers.</p> <p>The UniqueID must be unique to a particular client within the local authority. It may be the unique identifier used in the local authority's MIS or may be generated for the purposes of the data return. If the UniqueID is generated, it must be consistent to the client across all datasets returned for the carers' assessment data collection and the Social Care Survey and repeatable over time.</p> <p>Where a carer appears in more than one dataset, they should have the same UniqueID in each - this also applies to data relating to different years/quarters/etc. to allow for longitudinal analysis.</p>
CHI	Community Health Index (CHI) number for the	10-digit number	Optional <b>&lt;but need to provide other data if</b>

Variable Name	Description	Format/Values	Additional information
	<p>carer.</p> <p>The CHI is a population register, used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.</p> <p>The data provided will be one-way encrypted once the data has been uploaded to proxcd.net to protect patient privacy. This means that the Scottish Government will not be able to see the CHI number, but instead a string of numbers and characters.</p> <p>The encryption method used will be shared with the CHI Indexing teams at ISD Scotland and NHS Central Register to enable data linkage in future.</p>		<p><b><i>CHI not provided&gt;</i></b></p> <p>For data linkage/matching.</p>
Surname	<p>Surname/family name of carer. (Encryption?)</p> <p>The Scottish Government will use name data for data linkage purposes, but any datasets used for statistical analysis will not include name data.</p>	Character	For data linkage/matching.



Variable Name	Description	Format/Values	Additional information
Forename	<p>Forename/first name of carer. (Encryption?)</p> <p>The Scottish Government will use name data for data linkage purposes, but any datasets used for statistical analysis will not include name data.</p>	Character	For data linkage/matching.
Postcode	The postcode of the carer's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	<p>This must be provided for all carers.</p> <p>If carer's postcode is not known, enter NK01 0AA.</p> <p>For data linkage/matching and geographical analysis.</p>
PostcodeComp	The postcode of the carer's home address on the date that the assessment was completed, if different to the postcode in the previous field.		<p>This may not be necessary if the period of time between an assessment being requested/offered and being completed is relatively short.</p> <p>(Is there a good reason for including this in the data collection?)</p>
DateOfBirth	<p>Carer's Date of Birth</p> <p>Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for</p>	DD/MM/YYYY format.	<p>This must be provided for all carers.</p> <p>For analysis of data by age of carer.</p>

Variable Name	Description	Format/Values	Additional information
	data linking purposes.		
Gender	Gender of the carer.	1 - Male 2 - Female 99 - Not Known	This must be provided for all clients.  For analysis of data by gender of carer
EthnicGroup	<p data-bbox="360 475 1003 507">Ethnicity of the carer.</p> <p data-bbox="360 563 1003 938">To allow analysis of carer data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the Scotland Act 1998. The Race Relations (Amendment) Act 2000 puts a general statutory duty on public bodies, including the Scottish Government, to eliminate unlawful discrimination and to promote equality and good race relations.</p> <p data-bbox="360 994 1003 1241">This information will enable a national picture to be built of the ethnic background of carers, and this in turn will inform policy development and help the Scottish Government to address identified needs and to deploy resources appropriately.</p>	01 - White 02 - Mixed or multiple ethnic groups 03 - Asian, Asian Scottish or Asian British 04 - African, Caribbean or Black 05 - Other Ethnic Background 97 - Not Disclosed 99 - Not Known	<p data-bbox="1451 475 2094 507">Ethnic group must be provided for all carers.</p> <p data-bbox="1451 563 2110 683">The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth.</p> <p data-bbox="1451 738 2110 938">Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known).</p> <p data-bbox="1451 994 2110 1114">All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients.</p> <p data-bbox="1451 1169 2110 1321">To allow analysis of data by ethnicity for equalities purposes. (LAs need to take impact of having protected characteristic(s) into account - Carers Act S8(2)).</p>
CareHours	Number of hours of care that the carer	1 - up to 4 hours	This must be provided for all carers.

Variable Name	Description	Format/Values	Additional information
	<p>provides each week.</p> <p>(Exclude any caring that is done as part of paid employment or formal volunteering. If the carer provides care for more than one person, this should be the total amount of care provided.)</p>	<p>2 - 5 - 19 hours  3 - 20 - 34 hours  4 - 35 - 49 hours  5 - 50+ hours  9 - Not Known</p>	<p>Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))</p>
CareType	Type of care that the carer provides.	(To be determined.)	<p>This must be provided for all carers. (Multiple responses possible.)</p> <p>Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))</p>
CareLevel	The level of care that the carer is willing to provide.	<p>1 - up to 4 hours  2 - 5 - 19 hours  3 - 20 - 34 hours  4 - 35 - 49 hours  5 - 50+ hours  9 - Not Known</p>	<p>This must be provided for all carers.</p> <p>(Not sure if this variable should be included - this is something that LAs may not collect, and there may be potential data quality issues (e.g. consistency between LAs, data not provided for some/most carers).)</p> <p>Provides information on the extent of care that the carer is able/willing to provide (Carers Act s9(1)(b))</p>

### Cared-for person data

Section 9(1)(a)(i) of the Carers Act states that an ACSP must contain information about the nature and extent of the care provided or to be provided. This suggests that the data collected should contain information about the cared-for person as well as the carer, or the means to link carers assessment data to a cared-for person dataset (e.g. data from the Social Care Survey).

A Carer may care for more than one person. Multiple Cared for person records can be provided for each carer.

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers.
UniqueID	Unique identifier for the Cared for person	Numeric/Character	<p>This must be provided for all cared-for persons. If the cared-for person is already known to Social Work then this should be the same identifier used in the Social Care Survey.</p> <p>The cared-for person could also be a carer. Therefore the IDcarer and UniqueID variables should use the same unique identifier for each individual person to allow for identification of dual carer/cared for person relationships and to identify where there are multiple carers for one person or one person caring for multiple people.</p>
CHICFP	Community Health Index number for the cared-for person.	10-digit number	<p>Optional <b>&lt;but need to provide other data if CHI not provided&gt;</b></p> <p>For data linkage/matching.</p>

Variable Name	Description	Format/Values	Additional information
SurnameCFP	<p>Surname/family name of cared-for person. (Encryption?)</p> <p>The Scottish Government will use name data for data linkage purposes, but any datasets used for statistical analysis will not include name data.</p>	Character	For data linkage/matching.

Variable Name	Description	Format/Values	Additional information
ForenameCFP	<p>Forename/first name of cared-for person. (Encryption?)</p> <p>The Scottish Government will use name data for data linkage purposes, but any datasets used for statistical analysis will not include name data.</p>	Character	For data linkage/matching.
PostcodeCFP	The postcode of the cared-for person's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	<p>This must be provided for all carers.</p> <p>If carer's postcode is not known, enter NK01 0AA.</p> <p>For data linkage/matching and geographical analysis.</p>

<b>Variable Name</b>	<b>Description</b>	<b>Format/Values</b>	<b>Additional information</b>
DateOfBirthCFP	Cared-for person's Date of Birth Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for data linking purposes.	DD/MM/YYYY format.	This must be provided for all records.  For analysis of data by age of cared-for person.
GenderCFP	Gender of the cared-for person.	1 - Male 2 - Female 99 - Not Known	This must be provided for all clients.  For analysis of data by gender of cared-for person.

Variable Name	Description	Format/Values	Additional information
EthnicGroupCFP	<p data-bbox="376 213 640 293">Ethnicity of the cared-for person.</p> <p data-bbox="376 344 640 1410">To allow analysis of carer data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the Scotland Act 1998. The Race Relations (Amendment) Act 2000 puts a general statutory duty on public bodies, including the Scottish Government, to eliminate unlawful discrimination and to promote equality and good race relations.</p> <p data-bbox="376 1461 640 1583">This information will enable a national picture to</p>	<p data-bbox="649 213 931 245">01 - White</p> <p data-bbox="649 261 931 379">02 - Mixed or multiple ethnic groups</p> <p data-bbox="649 395 931 507">03 - Asian, Asian Scottish or Asian British</p> <p data-bbox="649 523 931 596">04 - African, Caribbean or Black</p> <p data-bbox="649 612 931 686">05 - Other Ethnic Background</p> <p data-bbox="649 702 931 734">97 - Not Disclosed</p> <p data-bbox="649 750 931 782">99 - Not Known</p>	<p data-bbox="940 213 2119 293">Ethnic group must be provided for all carers. The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth.</p> <p data-bbox="940 344 2119 469">Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known).</p> <p data-bbox="940 520 2119 596">All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients.</p> <p data-bbox="940 647 2119 679">To allow analysis of data by ethnicity for equalities purposes.</p>



Variable Name	Description	Format/Values	Additional information
ClientGroupCFP	Client group of the cared-for person.	01 - Dementia 02 - Mental Health Problems 03 - Learning Disability 04 - Physical Disability 05 - Addiction 06 - Palliative Care 08 - Problems arising from infirmity due to age 98 - Other vulnerable groups 99 - Not Known	At least one client group must be provided for all cared-for persons, and multiple client groups can be provided if applicable.  See Annex for descriptions of the client groups.  Provides (contextual) information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))

### Carer assessment data

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers.
CAReq	Was the carer assessment requested by the carer, or offered to the carer?	1 - Requested by carer 2 - Offered to carer	Must be provided for all records.  To provide information of the number/ proportion of reviews offered and requested.
CADate	Date that the carer assessment was requested/offered.	DD/MM/YYYY format (or whatever date format is appropriate).	Must be provided for all records.  To provide information about timescales for assessments and the distribution of requests/offers over the year.
CAType	Type of carer assessment.	1 - New 2 - Review	Must be provided for all records.  To differentiate between new assessments and reviews - will give an indication of time between reviews (when combined with request/offer date).
CAComplete	Has the carer assessment been completed?	1 - Yes 0 - No	Must be provided for all records.  To provide information on the number/ proportion of assessments completed.

<b>Variable Name</b>	<b>Description</b>	<b>Format/Values</b>	<b>Additional information</b>
CADeclined	Was the carer assessment declined?	1 - Yes 0 - No	Only required if CAComplete = No - must be provided for all of these records.  To provide information on the number/ proportion of assessments declined.
DeclineDate	Date that the carer assessment was declined	DD/MM/YYYY format.	Only required if CADeclined = Yes - must be provided for all of these records.  To provide information about timescales for assessments.
CADateComp	Date that carer assessment was completed.	DD/MM/YYYY format.	Only required if CAComplete = Yes - must be provided for all of these records.  To provide information about timescales for assessments.
CACarer	Did the carer assessment involve the cared-for person as well as the carer? (Alternative/better wording: Was the ACSP carried out as part of a joint assessment with the cared-for person?)	1 - Yes 0 - No	Only required if CAComplete = Yes - must be provided for all of these records.  To provide information about how assessment is carried out.

Variable Name	Description	Format/Values	Additional information
CAWilling	Is the carer willing and able to provide care for the cared-for person?	1 - Yes 0 - No (Other options?)	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>To give an indication of the proportion of carers who are not willing/able, as the people that they care for are more likely to need additional support in the future.</p>
CAEligible	Is the carer eligible for support? (There will be eligibility criteria to be met in order for the carer to receive support - does the carer meet these criteria at the time that the assessment was completed?)	1 - Yes 0 - No	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>To provide information about the number/proportion of carers assessed to need support who are eligible.</p>

Variable Name	Description	Format/Values	Additional information
CASupportNeeds	The support needs of the carer identified by the carer assessment	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/ support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Carer's allowance 10 - Other 11 - No help/support required	Only required if CAComplete = Yes - must be provided for all of these records.  (List taken from Scottish Health Survey questionnaire - could be altered or replaced to be more suitable/useful. Multiple responses possible.)  Provides information on carer's support needs (Carers Act S9(1)(f)), and if support should be provided in the form of a break from caring (S9(1)(k)).
CASuppNeedsOther	Other support needs not included in list of options for CASupportNeeds	Free text	Only required if CASupportNeeds = 10.

<b>Variable Name</b>	<b>Description</b>	<b>Format/Values</b>	<b>Additional information</b>
CASupportProv	The support that the local authority provides/intends to provide to the carer.	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Carer's allowance 10 - Other 11 - No help/support required	Only required if CAComplete = Yes - must be provided for all of these records.  (Same list as CASupportNeeds - multiple responses possible.)  Provides information on the support provided to the carer (Carers Act S9(1)(i/j)), and if support will be provided in the form of a break from caring (S9(1)(k)).
CASuppProvOther	Other support that the local authority provides/intends to provided to the carer.	Free text	Only required if CASupportProv = 10.
CAReviewOutcome	If the carer assessment was a review, has the assessment resulted in a change to the support provided?	1 - Yes 0 - No	Only required if CAComplete = Yes and CAType = Review  To provide information on the number/ proportion of reviews that result in a change to support.

Variable Name	Description	Format/Values	Additional information
CARReviewCrit	What conditions need to be met to trigger a review/reassessment?	(To be determined)	<p>Only required if CAComplete = Yes - must be provided for all of these records.</p> <p>(Multiple responses possible?)</p> <p>Provides information on what will trigger a review (Carers Act S9(1)(I)).</p>

### Additional data for YCS

Responsible authority/responsible local authority can be different for young carers. The responsible authority is the local authority in which the child resides (health board instead of LA for pre-school children), with some exceptions (Section 20 of the Act). Responsible local authority is the LA in which the cared-for person resides.

Variable Name	Description	Format/Values	Additional information
RespAuthority	The responsible authority for the young carer		Likely to be the same as the responsible local authority (LocalAuthority field) in most cases. Free text field, as this could potentially be a local authority, health board or school (so there are many possible options).
AppCare	The extent to which the responsible authority feels that the care provided by the young carer is appropriate.		Carers Act S15(1)(c)



## **Annex - Description of client groups**

### **1 - Dementia**

Global deterioration of intellectual functioning. Normally a progressive condition resulting in cognitive impairment ranging from some memory loss and confusion to complete dependence on others for all aspects of personal care. Exclude confusion due to other causes e.g. medicines, severe depression. Does not have to have been medically diagnosed.

### **2 - Mental Health Problems**

Mental health problems are characterised by one or more symptoms including: disturbance of mood (e.g. depression, anxiety), delusions, hallucinations, disorder of thought, sustained or repeated irrational behaviour.

Include: persons assessed as having mental health problems whether or not the symptoms are being controlled by medical treatment.

Exclude: alcohol or drug related problems; dementia.

### **3 - Learning Disability**

A significant, lifelong condition which has three facets: 1) significant impairment of intellectual functioning resulting in a reduced ability to understand new or complex information; 2) significant impairment of adaptive/social functioning resulting in a reduced ability to cope independently; and 3) which started before adulthood with a lasting effect on the individual's development.

### **4 - Physical Disability**

Physical disabilities have many causes in chronic illness, accidents, and impaired function of the nervous system, which, in particular physical or social environments, result in long term difficulties in mobility, hand function, personal care, other physical activities, communication, and participation.

Include: visual impairment, hearing impairment, severe epilepsy; limb loss; severe arthritis; diseases of the circulatory system (including heart disease); diseases of the central nervous system (e.g. strokes, multiple sclerosis, cerebral palsy, spina bifida and paraplegia).

Visual impairment. Blindness or partial sightedness (unless problems resolved by spectacles or contact lenses).

Hearing impairment. Profound or partial deafness and other difficulties in hearing (unless problems resolved by a hearing aid).

Exclude: Acquired brain injury. These clients should be classified under 'other'.

Problems arising from infirmity due to age. These clients should be recorded in the separate category.

## **5 - Addiction**

Alcohol-related problems - Any person who experiences social, psychological, physical, or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of alcohol.

Drugs-related problems - Any person who experiences social, psychological, physical or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of drugs or chemical substances.

## **6 - Palliative care** (as defined by the World Health Organisation)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. See <http://www.who.int/cancer/palliative/definition/en/> for full definition.

## **8 - Problems arising from infirmity due to age**

This category should only be used for clients aged 65 and over.

## **98 - Other vulnerable groups**

Clients should be included in this client group if they do not fall under the other categories for example clients with HIV/AIDS.

Acquired brain injury - Multiple disabilities acquired after birth arising from damage to the brain through head injury, stroke, lack of oxygen, infection, or other causes. People with an acquired brain injury usually have a complex mixture of physical, cognitive, emotional, and behavioural, disorders or difficulties. This may affect how the person perceives the world and their abilities to remember, concentrate, reason and judge. The person's emotional state may be disturbed; personality, behaviour, communication and relationships are also frequently altered. Mobility, sensation, vision, hearing and balance, smell and taste, respiration, heartbeat, and bowel and bladder control may also be affected.

## **99 - Not known**

If it is not known whether the person has been given a client group.

## Questions relating to data specification

Who should be included in the data submitted - all persons who are identified as being carers (irrespective of if they have an ACSP/YCS), all persons who have an ACSP/YCS in each data submission (so will include anyone who has had an ACSP/YCS, no matter when this took place), or all persons who have requested or been offered an ACSP/YCS?

- including all carers (including those without ACSP/YCS) would give the most complete dataset, but will LAs have data on the people who have not requested/been offered an ACSP/YCS?
- including data on those carers who have either not had an ACSP/YCS or have been offered one and refused will allow analysis of differences between carers who have had an ACSP/YCS and carers who do not

Some people who have had an ACSP/YCS will stop being carers (or may no longer be the responsibility of a local authority, e.g. if the cared-for person moves to another LA) - will this be picked up by LAs? If so, how should this be recorded?

Data for each individual carer, or an aggregate-level data return from each LA? (Spec has been written assuming individual-level data.)

- individual-level data is more detailed/complex, but will enable much more detailed (and useful!) analysis
- individual-level data should be available, as LAs should be recording operational data for each carer - data set out in the spec is based on the Carers Act, so should be collected as part of the assessment
- need to collect individual-level data in order to get to the aggregate data?

One collection for all carers, or separate collections for adult/young carers?

- are there enough differences between ACSP and YCS to justify having separate collections?
- there will be some young carers aged 18 or over (e.g. 18 and still at school), so can't just use age to split out the YCS records
- if the YCS is effectively the ACSP plus some additional stuff, could have a question to identify if the data is for an ACSP or a YCS, and use the response to this to include/exclude questions relevant to the YCS only

Should the data collection include anything on outcomes? ACSP and YCS should contain information about the carer's personal outcomes.

Potential for longitudinal analysis (i.e. looking at how each individual carer's position/situation changes over time) - would need to be able to link records in data submissions for different time periods.

Potential for linking this data to other (health) data

- obvious link would be to cared-for persons data - would give a more complete picture of both sides of care and care provision in Scotland (would ideally want to include some questions on the cared-for person in this data collection to provide background/contextual information about the carer's situation, but combining carers assessment data with cared-for person data would provide more detailed data)

Possible additional data to be collected:

- support available to carers and cared-for persons in the local authority (Section 9(1)(g)) - ask each local authority to provide data on this alongside the carers assessment data?

Where an individual is providing care to more than one cared-for person, data should be provided for each cared-for person separately. (Check this - may be more appropriate to collect 'combined' data for the care provided, particularly if there are relatively few people providing care to more than one cared-for person.)

Where more than one person is providing care to one cared-for person, data should be provided for each carer separately (as each carer should have their own ACSP/ YCS).

How do ACSP/YCS work where there is a) one carer for more than one cared-for person, b) more than one carer for a cared-for person, c) more than one carer for more than one cared-for person? How many carers are there likely to be who are in these scenarios?

Unusual/non-standard scenarios:

- a person has more than one ACSP/YCS in a data collection period - how should this be treated? (Ideally, we would want data on each assessment carried out, i.e. one record per assessment)
- a person provides care for two (or more) people who live in different local authorities - as the definition of 'responsible local authority' refers to the LA in which the cared-for person resides, does this mean that the carer will potentially receive ACSP/YCS from more than one LA?